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ABSTRACT

Story-telling, an oral tradition of the indigenous peoples of Australia, was recorded on video as a vehicle for conveying health promotion messages in several urban Aboriginal (Koori) communities in Sydney, Australia. The video was made by a group of Koori women Elders and two female Aboriginal academics. The Elders integrated their personal stories, which stressed the need for a healthy lifestyle, with information about preventative health care, particularly the processes of screening for cervical cancer and coronary heart disease. The placement of Aboriginal people in Australian society has resulted in a power imbalance that has permitted outsiders to define research problems and pose solutions with little consideration for Aboriginal control, needs, or interests. This research was conducted within the ethical guidelines for indigenous research developed by the Aboriginal Education Unit at the University of Sydney. These guidelines specify that: researchers should ensure through consultation and collaboration that the needs of Aboriginal people are met; Aboriginal communities shall have a principal role in decision making concerning research; research methodologies must reflect the group emphasis in Aboriginal communities; research materials and findings must be given to Aboriginal participants in research; and researchers shall observe cultural and customary rules in the Aboriginal communities involved. Adherence to these guidelines gave control, knowledge, and space to the older Aboriginal women to communicate important messages in their own way. (TD)

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Story Telling: Australian Indigenous Women's Means of Health Promotion

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STORY-TELLING: AUSTRALIAN INDIGENOUS WOMEN'S MEANS OF HEALTH PROMOTION

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SUMMARY

Story-telling, an oral tradition of the indigenous peoples of Australia, was used and recorded on video as a vehicle for conveying health promotion messages in several urban Aboriginal (Koori) communities in Sydney, Australia. A video (*Bullan Ngununggula - Women Belonging to Here)* was made by a group of Koori women Elders and two female Aboriginal academics with the assistance of other female academics in the disciplines of biochemistry, virology and epidemiology. The Elders integrated their personal stories which stressed the need for a healthy lifestyle, with information about preventive health care, particularly the processes of screening for cervical cancer and coronary heart disease. A viewing of the video will be followed by a discussion about the process of its production with emphasis on the ethical issues involved in Aboriginal research. As stated in the Koori *Principles and Procedures for the Conduct of Research*[1] it is imperative that the aims and objectives of indigenous research are integral to the overall program of health care and disease prevention in Aboriginal communities in Australia.

BACKGROUND

The health status of Aboriginals is poor in comparison to other Australians. Evidence for this includes higher infant mortality rates, higher morbidity rates and shorter life expectancy for Aboriginals than for non-Aboriginals. Despite the increased provision of clinical health services to Aboriginal communities over the last 15 years, significant reductions in mortality from conditions such as coronary heart disease, diabetes, and cancer have not occurred[2,3,4]. This failure has led many health care workers to advocate the need for research into the cultural attitudes affecting the utilisation of existing health services, and for targeting particular areas of concern. For example, efforts to provide adequate gynaecological care for all Aboriginal women is hampered by mainstream medicine's lack of knowledge of the concept of "women's business", which may hinder Aboriginal women from seeking assistance in matters relating to sexual and reproductive health, particularly if the providers are male and non-Aboriginal.
Two of the major disease problems currently affecting Aboriginal women are cervical cancer and coronary heart disease. The available data indicate that Aboriginal women have very high rates of invasive cervical cancer. The mortality rate for cervical cancer in Aboriginal women from various regions of Australia is up to four times the national average of 11/100,000[3]. The reasons for this high rate of fatal cervical disease are complex, but there is little doubt that low attendance rates for cervical screening and the effects of the established risk factors for cervical cancer (high smoking rates, poor nutrient status and a high rate of genital human papillomavirus infection) are of major importance[5,6,7,8].

When pre-contact Aboriginals adopted a Western lifestyle, both men and women developed an unusually high prevalence of coronary heart disease (CHD), obesity, and non-insulin-dependent-diabetes mellitis (NIDDM) [9,10,11]. The leading cause of death for Aboriginal males

and females in 1992 was cardiovascular disease, with males having 2.5 times more deaths than non-Aboriginals and females 3 times the expected rate[12]. It is important that programs which are designed to prevent rather than treat these conditions be implemented in Aboriginal communities.

A knowledge of both traditional and contemporary Aboriginal society is invaluable for the generation of effective health education programs. Traditional Aboriginal communities had no written traditions but instead possessed a vast store of oral narratives relating to the mythological Dreamtime. These were passed on from generation to generation by Elders in the community — the "Story-tellers". The stories reinforced cultural beliefs and appropriate behaviour, and also acted as aids for teaching people the practical skills required for survival in their nomadic life in a harsh environment[13].

For Aboriginal women the Auntie/niece Grandmother/granddaughter relationship was very important in the dissemination of information relating to "women's business", which encompasses female sexual and reproductive roles and practices. Story-telling by older women may therefore be a powerful tool for the dissemination of health promotion information in contemporary Aboriginal communities.

METHODOLOGY

In 1993 three of the Aboriginal authors (FA, JN and AT) received funding from the Australian Government for a project in which the concept of Story-telling was to be used as a means to raise awareness of particular health issues*[1]. These women were also involved in two collaborative projects with non-Aboriginal researchers: one investigating coronary heart disease (CHD) risk factors in Aboriginal women*[2]; and the other directed at increasing cervical cancer screening amongst Aboriginal women*[3]. In this presentation the process of both the collaborative research and the production of the story telling video will be related in the context of the ethical guidelines for indigenous research developed by the Aboriginal Education Unit (The Koori Centre) at the University of Sydney. As part of this process two Aboriginal community health workers had an increasingly important role in the production of the video: Dot Shipley and Patricia Heal. It is hard to give due acknowledgment to the contribution made by these Aboriginal workers and other community members as there is little appropriate space in standard practices applied to authorship in scientific papers. This is an example of the different cultural paradigms apparent in the conduct of Aboriginal research.

The Koori Centre's *Principles and Procedures for the Conduct of Research* (1993) were produced because of these differences and the perceived need for "a strong and fundamental commitment "to the conduct of research in ways which support and contribute to Aboriginal and Torres Strait Islander self determination". The important points of the *Principles and Procedures*, and the ways

in which these were complied with in the research project, are detailed as follows:

PRINCIPLES AND PROCEDURES FOR THE CONDUCT OF RESEARCH

"i. Researcher/s shall consult and collaborate with Aboriginal or Torres Strait Islander people, their community/ies, or organisations participating in the research project/s. Documentation on the process of consultation and collaboration shall be held by the researcher and produced on request."

"ii. The researcher/s shall ensure that through consultation and collaboration the needs and aspirations of the Aboriginal and Torres Strait Islander people, their community/ies, or organisation/s participating in the research are met."

"iii. The Aboriginal and Torres Strait Islander people, their community/ies or organisation/s involved in the research shall have a principal role in decision-making within the research project."

The project was presented in detail in written form to the University of Sydney's Koori Research Committee. Additional verbal explanation was provided as required. Preliminary discussions were also held with the Aboriginal Health workers at the Women's Health Centre (Liverpool) and Ganangarra Land Council (Canley Vale). Following its approval by the Koori Research Committee, numerous community meetings were organised to explain the project to the women involved, and to answer any questions or concerns that they expressed. Once the women in the community felt comfortable in their regular meetings with the researchers, discussions of various health issues revealed that coronary heart disease and cervical cancer were two of their most important concerns. As these concerns coincided with the existing research projects, a decision was made to focus on the ways these problems had directly affected the women's lives.

The overall objective of the Health Workers was to encourage a healthy lifestyle in the communities. They wanted to increase Aboriginal women's awareness of specific health issues, including obesity as a risk factor for coronary heart disease and the occurrence of cervical human papillomavirus infection as a risk factor for cervical cancer. The specific aim was to improve utilisation of available screening services by Aboriginal women in the immediate future. A more long-term objective was to use the model generated in this study to raise health awareness in communities of Aboriginal women elsewhere in Australia.

During the course of the project Audrey Trindall, one of the grant holders who is an Aboriginal graduate of the Diploma of Health Science (Aboriginal Health and Community Development) Course at Cumberland Campus, Faculty of Health Sciences, University of Sydney was also employed as a

research assistant on the allied CHD grant. Audrey was the initial contact person with the community. She had previously built up a working and trustful relationship with the women as she herself is from that community, and also had established good links with the other health professionals involved in the project.

"*iv. Researcher/s shall ensure the research methodology and the culture base from which it proceeds reflect the communal and collective system of Aboriginal or Torres Strait Islander communities.*"

The main factor taken into account when implementing this research project was that Koori women were to be involved in the project from its conception to its completion. Following consultation and discussion with the women in the community, The Koori Elders and community Health Workers the project followed the direction which they specified. Focus groups were initially held with the Elders in the local Aboriginal communities. There was lots of discussion and laughter. Group discussions led to further questions and requests for information. In addition to coronary heart disease and cervical cancer other health topics were discussed, including traditional health, experiences of childhood, stress and menopause, diabetes and nutrition, blood pressure, breast cancer, bladder infections and osteoporosis.

"*v. The researcher/s and the Aboriginal or Torres Strait Islander people, their community/ies or organisation/s shall negotiate a process for utilising the skills and knowledge base arising from the research.*"

At the meetings between researchers, Health workers and community Elders it was decided that the strategies most appropriate to achieve the objectives were:

- To provide information and knowledge in the area of health issues that concern women and use local Aboriginal Story Tellers in health provision and awareness.
- To produce a video about these issues for use in this and other Aboriginal and Torres Strait Islander communities.

The project was evaluated in the following ways:

- A questionnaire was distributed to all women who participated in the project. There was over 90% response to questions regarding knowledge gained, attitudes changed and behaviour altered by involvement in the project.
- Various panels of experts in the area of health promotion and womens' health gave verbal feed-back on the quality and usefulness of the video at the launch.

Already there are signs that a youth group now want to tell their stories regarding the issues they consider important.

"vi. Researcher/s shall provide evidence of a process for the dissemination of the research material and findings to the Aboriginal or Torres Strait Islander participants in the research."

The video *Bullan Ngunungguła* was handed back to the Koori Elders at a launch involving the Elders themselves, Aboriginal Health Workers, community health workers, senior academic staff of the University of Sydney and Griffith University, and Koori communities around Sydney who had helped make the research possible. This launch symbolised our relationship as so much was given, received, acknowledged and shared in the project.

"vii. Such information shall be provided by the researcher in formats and language which is appropriate to the communication system of the Aboriginal or Torres Strait Islander people, their community/ies or organisation/s."

The approach to research that was agreed upon was to adapt traditional Story-telling methods to the dissemination of health information. This strategy enabled the researchers to put information into a format and language which was appropriate to the special needs of Aboriginal women.

"viii. Researcher/s shall adhere to cultural and customary rules and laws in the Aboriginal or Torres Strait Islander community/ies involved."

The customs of the local communities were respected by all members of the research team. The various non-Aboriginal health specialists participated in the meetings only when requested to do so by the Elders. One issue which caused some initial concern was the fact that a male crew had to be used for the filming of the video, due to a lack of trained female personnel. The decision to allow males to be present was first discussed with the Elders and approved by them. The film crew became emotionally and personally involved when listening to the tales related by the Story-tellers. They had previously been unaware of many of the issues discussed by the women and the suffering that the Elders had experienced. Everyone involved in the project, especially the non-Aboriginal health specialists and the film crew were sensitive to the needs of the participants, and they learned more about Koori people during the making of the video. In this situation effective cross-cultural communication was an essential criterion.

"*ix. Researcher/s shall allow sufficient time for the research. The time specified in the research application must be agreed to by the Aboriginal or Torres Strait Islander participants in the research and provision must be made for consideration by the Aboriginal or Torres Strait Islander participants of the processes and outcomes of the research.*"

Appropriate time was allowed for discussion between Aboriginal and non-Aboriginal participants as they had to be flexible to accommodate cultural needs. Time was an important factor in developing a bond between the Koori women and the researchers.

"*x. Researcher/s must set out proposed benefits to the participant Aboriginal or Torres Strait Islander people, their community/ies, or organisation/s arising from the research process and outcomes.*"

Specifically, the project was of benefit to Aboriginal women in four ways:

- Aboriginal women living in the Liverpool region would accrue long-term benefits in their own improved health status as a result of the project's health education program prior to the Story Telling process. Further, awareness of the dangers of obesity and of the benefits of increased screening for blood cholesterol and cervical papillomavirus infection should lead to a reduction in the development of these diseases among Aboriginal women.

- Aboriginal women generally would benefit in similar ways if they adopted the model for women's health education that this project developed.

- Aboriginal women more broadly would benefit from the empowerment they gain in being able to develop and implement a culturally and locally appropriate health awareness program; and from the networking between their community groups and the University that this project would foster.

- In both CHD/ Diabetes and Cervical Cancer projects there is ongoing contact and consultation between the researchers and the original participants. In some cases this has entailed individual discussion of clinical results and in others group education on specific health issues associated with the projects and requested by the communities. Thus this ongoing contact ensures that appropriate follow-up mechanisms are maintained with continuing advice and consultation available.

DISCUSSION AND THEORETICAL ISSUES

Much of the research that has been undertaken in this country has occurred for purposes outside Aboriginal control, needs or interests. Once one looks closely at what has and is occurring in the area of research it becomes very clear that research is done on Aboriginal groups. In the majority of cases those with power have defined the 'problem', designed the methodology and blindly blundered on to write the solution.

The placement of Aboriginal people in Australian society has ensured that they have little ownership of the issue, no input into methodology, and thus, processes of inquiry and control of outcomes. Most importantly, the process arising out of such approaches has stumbled across indigenous protocols and practices with no sight or thought of the ultimate negative impacts on peoples lives and society as a whole. The power imbalance has permitted 'outsiders ' to define the problem and pose the solutions with little challenge to methodological, or ethical issues.

Today many indigenous academics are moving into the field of research and the path is difficult. We too can fall into similar traps through the theoretical position being taken, the methodology used and the cultural baggage we carry as individuals. This, like for Others, can blind Aboriginal people to important protocols and practices, can place us as 'outsider' and force us to use processes that are totally inappropriate. Despite these issues we need to move forward in the field of research to ensure that we control and, in other instances, are active and equal participants in the research process[13].

Through engagement in this way indigenous people can own and control each and every step of the way and own their outcomes. In this project the approach taken allowed for the bringing together of new knowledge with indigenous ways; acknowledged the status of elders, permitted information to be used by participants in their own lives and reinforced cultural identity.

The aim of this project was to document and recommend culturally appropriate ways to improve Aboriginal women's health status. Clearly, the approach taken gave control, knowledge and space to the older Aboriginal women to communicate important messages in their way.. Some of the conclusions can be summarised in the following way :

- There is a need to encourage training and education.

- Aboriginal Health Workers want to develop knowledge and skills in western concepts of health and illness but they have concerns of maintaining Aboriginality while ensuring they provide the best medical care. They face a conflict between a medical model of health care and a cultural model of health care which is grounded in a philosophy of caring and sharing based on relationships. Aboriginal Health Workers need to be recognised with more than a token gesture and mechanisms should be put into place to ensure this recognition.

- Aboriginal women's health needs to be targeted in a culturally appropriate manner, which in this paper is identified as small group, sharing of knowledge and time to develop trust, ensuring people of status have control and that relevant language and communication techniques are utilised.

As well important theoretical issues arose. Such issues are embedded in the philosophy of Aboriginal societies and give rise to a 'holistic' view of health in many Aboriginal cultures. As clearly stated by one of the authors of this paper and her colleagues:

- In Aboriginal consciousness health is recognised as broader than physical health although inclusive of it. Health and illness are interpreted in relation to dislocation from the land and the subsequent loss of cultural continuity this engendered. Although many women perceive themselves in terms of a past beyond the colonial period, the devastation and the long term implications of that encounter are never far from their minds.
- The social and cultural positioning of Aboriginality within a colonial context emerges as a dominant theme. For urban Aboriginal women, strong self-identification as an Aboriginal woman is the first step towards taking control of their health[14].

As well the family is central in Aboriginal women's perception of themselves, their Aboriginality and their health problems. Women have a responsibility to care for husband, children and other family members and this is often undertaken to the detriment of their own health. Therefore, women's health or ill- health is closely linked to near and distant kin and the well being of their family.

Despite these theoretical concerns this project allowed a group of Aboriginal women to strongly affirm themselves thus, permitting a process to emerge to deal with major health worries and concerns.

Further, a Story was developed to pass on the same knowledge to others.

Most important is that the methodology and process used gave the elders control, knowledge, empowerment and ultimately a reinforcement of themselves and their way.

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*[1]*Department of the Prime Minister and Cabinet- National Agenda For Women Grants Program 1993* $11,500 Acklin F, Newman J, Trindal A : Story Telling to raise awareness of certain health issues and health Screening for Aboriginal women

*[2]*Sydney University Mechanism B Infrastructure Grant 1992* $25,000 Brock K, Arbon V, Cossart Y, McKinnon K: Cervical Cancer in Aboriginal and Asian Women

*[2]*National Health and Medical Research Council Public Health Research Development Council Grant 1996-8* $150,000 Brock K, Acklin F, Thompson C, Mindel A: Cervical pre-cancer in Koori Women

*[3]*Faculty of Health Sciences Research Grants 1992-1994* $20,000 Bermingham M, Brock K, Acklin F, Newman J, TranDinh H: CHD and Diabetes Risk Factors in Aboriginal Women

*[3]*University of Sydney Research Grant 1995-6* $25.000 Bermingham M: CHD and Diabetes Risk Factors in Aboriginal Women- a follow-up.

*[3]*National Health and Medical Research Council Public Health Research Development Council Small Grant 1994* $20.000 Bermingham M, Brock K, Acklin F, Newman J: CHD and Diabetes Risk Factors in Aboriginal Women

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